# THE CLOSER

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# **CONNECT FUND Impact Report**

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WE GET

OFFICIAL SELECTION POTDOCS

### Introduction

**The Closer We Get** is a powerful, award-winning autobiographical documentary that has gained international critical and popular acclaim and a BBC broadcast since its premiere at 2015's Hot Docs festival in Toronto, Canada.

Ann, director Karen's mother, suffers a devastating stroke that brings her daughter back home when she least expects it. But Karen isn't the only one who returns to help care for Ann in the crisis. Her prodigal father lan - endearing and unfathomable - and who's been separated from Ann for years, also reappears. Armed with her camera, Karen seizes this last chance to go under the skin of the family story before it's too late, finding that Ann's stroke has in fact thrown them all a life raft.

**Somewhere**, the multidisciplinary creative organisation led by director / producers **Karen Guthrie** and **Nina Pope**, received a Bertha BRITDOC Connect Fund award in May 2016 to continue the impact work linked to **The Closer We Get**.

"A very powerful film and a brave presentation by Karen showing the difficulties of being a carer and the effect of stroke on a family unit."

"The Closer We Get presented a very personal story that challenged the role of professionals and depicted the importance of the role of family members as carers. The discussions on what does work for people and families dealing with stroke highlighted what services should be offered and what could be done differently."

"Very emotive and as a nurse the film has certainly enhanced my understanding of the experiences families deal with." Feedback from Glasgow Caledonian University's 'Life After Stroke Open Day' – May 20, 2016

Feedback from Glasgow Caledonian University's "Life After Stroke Open Day" – May 20, 2016

At the time of applying to the **Bertha BRITDOC Connect Fund,** director Karen had already led over thirty post-screening Q&A's in contexts ranging from stroke survivor support groups to mainstream cinemas, international film festivals, NHS training groups and a youth film workshop.

Karen's willingness to present the film in person and to openly tackle any question and topic (at times accompanied by family members from the film, able to do likewise) had lead to dynamic and moving experiences for everyone in the room. This contact - over a sustained period of approx. 14 months - with such a wide-ranging and international audience became a prolonged road test that nurtured Karen's ambitions for outreach linked to the film, and helped her find a language with which to discuss the complex and sensitive issues of family dynamics, disability and ageing, with both a general public and specialist audiences from a stroke / social care background.

Our Connect Fund-supported activity intended to build on a previous programme of modest outreach work supported by **Big Lottery Scotland**, and to further exploit bespoke resources we had created for this work. Our intention was to set the film to work as an educational resource for the right influencers, networks and stakeholders who themselves reach health and social care workers in the UK.

#### We had available for our Connect Fund-supported activity:

### The feature doc The Closer We Get (with all rights except UK TV retained by Somewhere) in both 87' cinema & 48' TV cuts

A UK cinema release in 2015, BBC Scotland broadcast in 2016, international prizes and unusually long film festival run (15+ countries across two and a half years) combined with its exemplary reviews and coverage in the mainstream UK media, offered an opportunity for outreach that could be driven by the considerable momentum of this critical and peer acclaim.

#### Film Extras - eight short clips of material shot for, but not included in, the film

Somewhere had begun their outreach work with a short run of screenings and workshops mainly with stroke support groups in Scotland, supported by the Big Lottery Awards for All. This suite of accessible and stroke-specific clips was created for these events and to help develop other educational opportunities amongst healthcare professionals. They were produced with editorial support from the charity **Chest**, **Heart & Stroke Scotland** (CHSS) which coordinates many of Scotland's support groups and offers healthcare training on stroke in Scotland.

#### An enthusiastic and confident director advocating for the film's issues

Karen Guthrie's powerful personal relationship to the film cannot be overstated as an asset to our work. Her capacity to speak about her experiences both as a film-maker and as a carer has been of great importance in sustaining the outreach across a long period of time, and in being able to offer an authentic and compelling programme of activity that stands out from much other social impact film, and from the generally-available training in health and social care. The film's story has also attracted sustained media interest which reached mainstream audiences (e.g Karen's appearances on BBC Radio 4's 'Midweek' & 'Women's Hour') with a resultant positive impact on all aspects of our distribution and impact work.

### Summary

Our Bertha-supported impact activity was designed to exploit these existing assets by:

- Producing and distributing a DVD of the Extras clips
- Producing supporting documents to extend the clips into a measurable training resource
- Devising, delivering and evaluating a Carer Training Pilot (aka See Beyond Stroke) using these resources
- Enabling Karen to attend, network and speak at significant UK healthcare events chiefly the UK Stroke Forum (organised by the Stroke Association)
- Creating and distributing presentation and marketing materials for relevant events and conferences

### Team Profile

The Bertha-supported outreach activity was delivered by:

#### Karen Guthrie - Director / Producer

Karen had devised and delivered programmes that had brought previous films to specialist sectors such as social care, and had secured the Big Lottery Scotland support for the film's first phase of impact work.

#### Sally Hodgson - Distribution Producer

In 2010, and following a seven year stint at one of the UK's Regional Screen Agencies, Sally started working with filmmakers interested in exploiting opportunities to do things independently and with innovation. Since then she has released films theatrically, brokered broadcast sales, built grassroot audiences and run successful audience engagement campaigns.

#### Jennifer Skinner - Outreach & Evaluation Coordinator

Jen has 16 years experience in film exhibition, from managing a venue to developing the film education programme at the National Media Museum. She has been freelance for the last 3 years working across the independent film sector with various organisations including the Independent Cinema Office, BFI and Into Film, which brings films to younger audiences.

### Aims & Objectives

In our application to the Connect Fund we set out the following challenges :

#### 1. What problems are we trying to solve?

Raise awareness of stroke and to make a change in the current provision of care from management through to individual person-centred care programs and support for stroke survivors and their carers.

#### 2. What would make a change?

Decision makers, carers, stroke survivors and those who haven't even considered the possibility of stroke having a chance to think and discuss the impact for all those involved and how they can work together to improve current provision.

#### 3. How do we plan to make a change?

Screening the film as widely as possible to Local Authorities, Health Care Professionals, Families and Carers and Stroke Survivors and evaluating responses.

#### 4. What results do we want to see?

The film being used in carer training in 20 local authorities (across England, Scotland, N Ireland & Wales) and being disseminated by them to as many people involved in their local care provision as possible.

#### 5. How can we measure progress?

By recording the number of Local Authorities reached and closely monitoring their responses. Through them, by recording the number of healthcare professionals, carers, stroke survivors and families reached, by gathering their responses and building a picture of the impact from there.



**The Closer We Get** Production still by Nina Pope

# STRAND ONE: UK Stroke Forum 2016

This annual three-day event is attended by a coalition of over 30 organisations committed to improving stroke care in the UK. It took place in December 2016 and welcomed 1505 delegates. We delivered:

- A presentation by Karen Guthrie
- An 'Extras DVD' Giveaway
- A discount code to independently watch *The Closer We Get* online

### 1.1

#### Presentation: 'The Closer We Get – Getting to know Mum after a Stroke'

By Karen Guthrie and chaired by Chris Larkin, Regional Director for Stroke Association North West.

- Well-attended session with 60 delegates present
- The cinema trailer of the film and two clips from our See Beyond Stroke training resource were screened followed by a Powerpoint presentation
- Karen presented the format and results of post-screening workshops with various groups to date stroke survivors, their informal carers, and with stroke healthcare professionals, highlighting the most common and most surprising feedback from each group
- Karen then outlined the ongoing impact activities being delivered with Bertha BRITDOC Connect support & appealed to delegates to help reach those in charge of local authority carer training, and to anyone present who may want to use the See Beyond Stroke resource in their own workplace
- Optional Feedback Forms were available for completion and return in situ. (See Appendix 1 Feedback from UK Stroke Forum)
- Chris facilitated a closing question & answer session between the audience and Karen, the salient points of which can be summarised as: The lack of availability of counselling support offered to Karen's family after her mother's stroke;

The scarcity of educational materials on stroke that are relevant to a family, especially in the immediate aftermath of the stroke when the family is in shock;

How the clips clearly showed the benefits to Ann (and to her family too) of her being cared for at home despite her severe disabilities and their incumbent risks;

The clips evidenced the therapeutic effects of filming and / or creative activity shared by carer and stroke survivor, and that recording activity and achievements and replaying them to stroke survivors could be motivational for them (Some delegates had engaged in this informally in their work or encouraged families they were working with to do so too);

A clip that was shown (The Million Women Study) was especially appreciated as a richly-nuanced and entertaining portrayal of the psychological complexity of a stroke survivor's sense of identity, powerful in its capacity to build empathy in the formal education of trainee nurses and doctors as well as in ongoing CPD for those further along in their careers.

Additional verbal feedback received by Karen after the session demonstrated that some people were concerned about a lack of available funds to license the film and extras for teaching and CPD purposes. Karen suggested that individuals approach their institutional libraries (where they had one - e.g. at universities) and ask them to acquire the film. However, this was not a solution / link people made themselves and may be an indicator to why educational take-up has been slow despite obvious enthusiasm from many people.

#### 'Extras DVD' Giveaway

Each Stroke Forum delegate received a free DVD copy of the eight film clips within the See Beyond Stroke resource, plus a flyer outlining the resource and including clear contact information within their official Stroke Forum delegate pack. The DVD packaging provided a 40% discount code to watch **The Closer We Get** online or download it for a limited time period.

#### Watch The Closer We Get discount code

The DVD discount code, valid after the Forum from 24 November to 31 December 2016, significantly discounted the film via Vimeo On Demand - therefore, a single online watch would cost £1.60 to rent and £2.80 to buy. Our self-distribution has to date chiefly been via Vimeo and Amazon, and we chose Vimeo On Demand for this promotion as it offers fully accessible functionality in order to set-up and monitor discount codes as well as the optimum financial return. Unfortunately, none of the delegates took up the offer of a discount to watch the film. We can only guess at the reasons inhibiting take-up, but we suspect them to be chiefly that Vimeo is a comparatively unfamiliar platform to consumers (compared to iTunes or Amazon, for example), and it requires the set-up of an account and hence some password / email validation processing in order to access the film.

### 1.2 Evaluation & Feedback

There were several routes for receiving attendees responses to Karen's session and our overall involvement in the Stroke Forum:

1. **Directly** - verbally to Karen during the event, through direct email or delegates seeking out and using our website contact form

2. The optional **Feedback Form** completed by and collected from attendees immediately after Karen's session

3. Via the **Stroke Association's full event evaluation questionnaire** sent to every delegate by email on the event's final day & available on the conference app. This evaluation questionnaire was quite extensive and linked to attendees' CPD, and hence we were unfortunately only able to include a single question in it.

#### 1. Via direct email:

"I was a delegate at this week's UK Stroke Forum. I attended the session with Karen ..... absolutely fantastic and as a coordinator who supports stroke survivors and their carers/family members, I feel the film will be an extremely useful training tool to provide insight into real life situations." Julie Sartorius, Information Advice & Support Coordinator, Wirral - Stroke Association

#### 2. Via our Feedback Form

Attendees of the session were invited to complete a quick Feedback Form on the spot which gave us the most meaningful insights into the impact of the event.

Here are some excerpts:-

What message does the film offer healthcare professionals, including carers? *Hope, impact, a conversation starter, a training tool'* 

'It is sometimes difficult for therapy instructions to be followed through at home in the exact way the therapist intended. Therapists need to work with the stroke survivors and families to make instructions more realistic to achieve at home.'

'Think it would be incredibly important for professionals in a hospital setting and at home to remind people that everyone is an individual and stoke impacts a huge network of people around the stroke survivors in such a difficult environment in NHS and LA's.'

After watching these clips is there anything that you would do differently? 'I work with stroke survivors and carers but in a management capacity. I will use the clips with teams and work harder to put the carer and their loved one above the paperwork' 'Would love to use this and train care home staff and home carers'

What needs to change? 'Support to train in social care'

How can we make a change?

'As many people as possible need to see the film and engage with it. I definitely agree that consultants and commissioners would benefit'

'Accredited stroke training which is not expensive, to allow care staff to access it.'

An interesting general comment on this session was:

'Could this talk be added to one of the plenary sessions to capitalise on the large male audience? In the same way that we had the talk by stroke survivors?'

Karen's session was attended by an overwhelmingly female audience although the Forum attendees in general were of an even gender balance.

#### 3. The Stroke Association's own Evaluation Questionnaire

A total of 665 responses (from 1505 delegates) were received by the Stroke Association to their Evaluation that was sent out to delegates to gather feedback on the event as a whole.

We arranged to include a question about our session specifically. This question was not mandatory.

Our question was:

'With reference to the DVD of 'See Beyond Stroke' clips you received in your delegate pack:

The creators of See Beyond Stroke can offer engaging film-based training tailored to your specific requirements. Are you interested in finding out how film content could be used as a learning resource within your area of work?'

Recipients were given option to answer 'yes' or 'no' with 96 responses for 'yes' and 236 responses for 'no'. (**A full breakdown by job / role can be found in Appendix 2**)

Respondent groups within healthcare that showed the highest level of interest in our resources were physiotherapists, nurses and physicians. This possibly reflects the general nature of their practice and training, with little access to stroke-specific training or to the nuanced, patient-centred materials we offer, despite a clear appetite for it.

Attendees who answered Yes were encouraged to contact us directly and provided with an email address. However, due to data protection laws the Stroke Association was unable to share delegate email addresses for follow-up after the event, and hence delegates would have needed to instigate contact with us.

The inclusion of the DVD plus a flyer about our outreach activities in the delegate pack did lead to a number of direct enquiries that in turn resulted in training activity, including the following.

"We were impressed by the presentation of The Closer We Get by Karen. We think that it would be a great idea to try and organise a screening of your film at Frimley Park Hospital in Surrey."

Alex Christiansen, Senior Physiotherapist, Frimley Health NHS Foundation Trust

### 1.3 UK Stroke Forum - What We Learnt

- It could be worthwhile to target future training offers at the professional bodies representing physiotherapists, nurses and physicians or to their training providers these groups having stated a clear appetite for it in the SF evaluation.
- Data protection rules which prevented contact-sharing between other parties and us had a significant impact on how well we could exploit this event. Had we been able to directly contact the 96 positive Stroke Forum respondents and follow up with them, we could have achieved many more concrete outcomes. Future work should take into account how to overcome this hurdle.
- Karen's presentation of the film and training opportunities / achievements to date is highly engaging, yet securing proactive follow-up activity from delegates was challenging and would require further resources to pursue persistently. Karen sent 20+ personal emails to relevant delegates after the event, with negligible results.
- Vimeo is not a consumer-friendly distribution platform perhaps an Amazon download, or a free DVD of the film would have been more accessible, and hence could have generated more word-of-mouth recommendations that may have lead to outcomes?
- Despite strong initial interest in more than one in three delegates who responded to the Evaluation question we set, healthcare professionals and academics are not motivated to watch even a relevant film in their own time. Reducing its cost had no effect on take up.
- The giveaway DVD indirectly proved a useful marketing tool a subsequent enquiry leading to a training session originated in it jogging someone's memory and instigating contact.
- By distributing the giveaway DVD so freely, a key part of the training resource was already with potential users. Therefore we cut down on the amount of administrative work during the course of the project as we could simply email the paperwork they needed to run the training using the DVD of clips.
- A significant error we made on our Stroke Forum Feedback Form was offering our contact on the sheet that they handed back to us and not requesting theirs. We received some interesting comments that we couldn't follow up on.

### 1.4 Associated Outcomes

Participating in the UK Stroke Forum – the Stroke Association's key annual event – reinforced our connections to the organisation and led to introductions to key personnel within the Stroke Association's Event Team. As a result we gained a presence at a number of other Stroke Association events and at activities by other organisations in the field. The main associated outcomes were:

#### 1. Widespread Distribution of Marketing Materials to Relevant Target Groups

The contacts we made at the UK Stroke Forum lead to a presence at these further events:

The Stroke Association deliver commissioned stroke training masterclasses in a number of UK local authorities. Our SBS flyer was included in their delegate bags at three training events that took place in Cardiff - February 15th, Stirling - March 1st, and Cheshire - March, 29th. Attendees (165) included Stroke Specialist Nurses, Stroke Research Nurses, Care Services Managers and Stroke Liaison Nurses within the NHS and at University Health Boards and Hospital Trusts.

ALLIANCE Conference - Change: the Health and Social Care Integration, organised by Health and Social Care Alliance Scotland. Glasgow - May 30, 2017. Attendees – 200. Distributed our marketing materials.

14th Congress of the European Forum for Research in Rehabilitation, organised by the Society for Research in Rehabilitation and the British Society of Rehabilitation Medicine. Glasgow - May 24 - 27, 2017. Attendees - 300. Distributed our marketing materials.

Welsh Stroke Conference, one of the biggest multidisciplinary care events in Wales and a significant fixture in the educational calendar for Stroke in the UK. Organised on behalf of the Welsh Association of Stroke Physicians and the Welsh Stroke Alliance. Cardiff - July 3 & 4, 2017. Attendees – 300. Distributed marketing materials.

Total number of people reached through attendance and marketing presence at events and conferences: 2,600

#### 2. Invitation to Stroke Assembly North

Karen was invited to this two day event (May 30 & 31, 2017) organised by the Stroke Association and aimed largely at family / informal carers and people affected by stroke. Attendees numbered approx. 130. On the inaugural evening Karen was one of three keynote speakers in the 'Stories of Stroke' session and provided an overview of the film and ongoing outreach work. On the second day Karen had a stand within the main conference area to provide more detail about the SBS resource, demonstrating the resource materials to interested parties and to also sell DVDs of the film. As a result of this event, Karen has been invited by the Scottish branch of the Stroke Association to be a keynote speaker at their Assembly later in 2017. Ten copies of The Closer We Get DVD were also sold.

### STRAND TWO: Carer Training Pilot aka See Beyond Stroke

#### Summary of Planned Activity:

- 1. Produce an accessible training Resource Kit to support the existing film Extras
- 2. Distribute the Kit to Local Authority carer trainers and outsourced private care companies delivering adult domiciliary care to stroke survivors
- 3. Support, monitor and evaluate their use of the Kit
- 4. Monitor the project's challenges closely and track our team's time commitment to this Strand, in order to share learning with our peer group, plan future impact work realistically, and to contribute to the body of evidence on film impact work in the UK



**See Beyond Stroke** Resource Kit

# 2.1 Content

#### Our goal was to,

"influence the attitudes and behaviours of health and social care workers towards the survivors of stroke (and other life-changing or life-limiting illnesses) and to their unpaid carers."

We wanted to reach those at the frontline of day-to-day care, aware that their access to training is limited by many factors. Our previous feedback from health and social care professionals had demonstrated that training tools that convey the dynamic of 'being cared for' were non-existent and much needed given the recent emphasis throughout the NHS on adopting patient-centred care pathways.

This is where **The Closer We Get** could make a difference, and how the pilot training project based on See Beyond Stroke (SBS) was devised.

#### The Resource Kit

We produced a set of See Beyond Stroke resources to extend the pre-existing Extras (online and on DVD short video clips 2-3 minutes each, eight in total) each of which had a clear learning outcome. Each clip addresses specific stroke-related issues, e.g. food and diet, physiotherapy at home, the impact of stroke on the family unit and mental health/ wellbeing.

These additional worksheets were produced as downloadable PDFs or optionally we offered to post print outs where necessary:

- How To Guide providing guidance on the four steps involved in using the SBS resource within a training environment or in the workplace.
- Carer Worksheet created from our experiences of sharing the film throughout all our outreach activity. We worked with advisors from stroke care, medicine, social care and public engagement and added our own guidance for discussion topics before, during and after screening the Extra Materials.
- Trainer Evaluation Form to gather feedback from people delivering SBS within a training setting.

We also created an Overview 'one-pager' sheet to summarise and promote the resources more easily than we could in a general email or a cold call, and an optional Certificate of Completion, developed in response to a suggestion from a carer trainer. This can be filled in and issued by team leaders, given to participants and copied for their HR files as evidence of training.

It is important to stress that the Pilot was designed as stand-alone project, to function without trainees needing to watch *The Closer We Get*, which at 87' is prohibitively long for most carer training contexts. Pilot participant trainers were offered a screening copy of the full film as an option. This offer was taken up by 1 in 3 Local Authorities and/or organisations, although it is possible that other routes to viewing the film were taken without our knowledge.

# 2.2 Distribution

### Our goal was to distribute the kit to carers operating in 20 Local Authorities throughout the UK.

At the time of writing a total of 14 Local Authorities have either run the training or have it scheduled. Approximately 700 people to date have receiving the training. This figure will increase as some has not yet been delivered. We estimate that close to 1,000 people will receive the training in total by the end of the Pilot.

#### (The Local Authorities involved are listed in Appendix 4).

We made initial contact with 68 of the 109 UK Local Authorities. We established that there are many differences in provision across the country, and discovering that many now out-source all adult social care to private contractors, with whom we would need to make individual contact to offer the Pilot activity.

To maximise the efficiency of our small team, our initial focus was then reviewed in line with the contacts made and the feedback received from our participation the UK Stroke Forum, leading us to focus effort on places where our contacts informed us there was likely to be interest and take-up. This did mean, however, we were unable to respond to data that a larger pilot may have been able to prioritise: For example, aiming to deliver the activity in areas with a comparatively high incidence of stroke, or where there are high numbers of adult stroke survivors receiving care at home.

The team then moved onto direct contact with certain Local Authorities, building on the previous desk research with the aim of reaching the people who commission and/or deliver their carer training. This was much more time-consuming than anticipated, and we successfully exploited personal contacts wherever possible to reach decision-makers - for example, in North Ayrshire where the film was made, or Cumbria, where director Karen lives, and Birmingham, where Karen had a personal contact in social care.

We came across a number of significant challenges when working to secure training sessions with Local Authorities (LAs).

- LAs don't all operate the same way and information on their care delivery approach is seldom readily available via desk research. Much time was spent trying to track down the right person to find out that the training is outsourced.
- Outsourced private care companies vary in their appetite for and capacity to take on additional training.
- Relying on email addresses and sometimes these being generic and not personal addresses.
- Lots of cold calling and quite a complex project to explain in brief.
- Calling general info/support lines and being caught up in caller options.
- Person picking up the phone isn't always the decision-maker/budget holder.
- Part-time and limited time from our team meant we were dipping in and out of this project and so difficult to generally catch people at their desks with the time to talk about the project.
- Some LAs use only Stroke Association accredited training.
- Timescales of training activity with the organisations and providers we got through to sometimes their training scheduling was out of the scope of the timing of this project.

# 2.3 Support, Monitoring & Evaluation

With limited time, staff and resources we were aiming to devise a resource with maximum impact that could be used independently across a range of settings, with the resource offering some flexibility to meet the specific needs of people running the training - i.e. we were initially offering bespoke resources such as Discussion Worksheets with specific emphases or film clip selections to suit particular care settings.

Through our initial contact with potential training providers we quickly realised that this aim would result in delays to the project:

We would have needed to spend time generating these resources, keeping warm leads interested and meeting their training deadlines in terms of time-tabling, on top of contacting new leads and gathering and collating feedback. Therefore we decided to devise a resource that we felt would best meet the needs of *most* of these training providers if not all.

Our kit was not typical in current training provision - i.e. film clips and a suggested discussion structure - so sometimes there wasn't a good space or the equipment required to play the clips. Getting people in same place and having someone within the team willing/ able to deliver the training was tricky too and the nature of intended participants jobs (domiciliary care etc) meant that they rarely got together as a group, and when they did there was already a full agenda in place for these team meet-ups.

The lack of IT support and equipment for our target group also presented a challenge, as we did try to encourage training managers and decision makers to share our resource through online channels. Many people working in care provision do not have computer equipment that is able to facilitate access to online training materials.

#### Gathering Feedback

In our original application we proposed a number of methods for gathering feedback. We detail here the success of these:

#### a. Questionnaires

We anticipated using bespoke to each scenario and end-user - some in-depth, some quick response style. All aimed at gauging initial response. We considered using Twitter to gather initial responses then using paper based questionnaires during sessions and an online tool like Survey Monkey for follow-up responses.

# *In practice:* Initial responses about SBS were gathered via phone calls or emails. Through this early phase of the project and from previous experience of reactions from screenings and workshops and from the focus group activity (see below), a final set of paper-based questionnaires were created - the Carer Worksheet and the Trainer Feedback form. These documents provided prompts for group discussion during the training session, space for comments and thoughts from participants and data gathering questions. The documents also provided us with quantitative and qualitative data.

The documents along with the Overview and How To documents were provided as a package of PDFs, therefore easy for the team to email and/or download from the See Beyond Stroke webpage.

We found it difficult across all our Connect Fund activity to engender social media en-

gagement, although we have a reasonable number of followers; often posted the relevant hashtags ourselves; and always included the Facebook and Twitter addresses in printed and online media and in verbal presentations. Therefore we decided not to rely on Twitter to gather responses to and feedback on SBS.

#### b. Focus Groups

We proposed fully facilitated, small sessions with 6 to 10 people using set questions to enable free flowing answers. We would aim to bring together people who do not already know each other to enable free discussion.

#### In practice:

Jennifer Skinner led a focus group on Tiree with local authority carers and the manager of the local care home. The feedback from this session informed the development of the resources further, guiding us towards altering some language and the style of discussion prompts/questions. Consequently, Jennifer was able to specifically recommend that we provide a separate sheet inviting trainees to write directly on to it. This become the Carer Worksheet (*see Appendix 3*). This could then be returned us to enable easy monitoring of the impact of the resource. To gather feedback on the viability of the resource as a whole we also created the Trainer Feedback Form (*see Appendix 3*) which gathered specific contact information and invited suggestions for improvements.

#### c. Case Studies

We anticipated highlighting situations we encountered through delivering the activity that we believed warrant exploring in further detail.

In practice:

This would have been too time-consuming to deliver effectively given the communication difficulties we experienced with our trainers and trainees.

#### d. Evaluation Workshops & Review Meetings

Working with the local authorities and other key contributors to feed into the final evaluation, we were aiming to specifically look at any obstacles encountered and how to plan comparable future work.

In practice:

This activity did not happen due to time constraints on both sides - our team was already stretched in trying to achieve the target of 20 Local Authorities. Those Local Authorities that did run the training used what time they could dedicate to running the training and completing the worksheets, and were unable / unwilling to dedicate more time to evaluation.

#### e. In-depth Interviews

These were to be carried out over the phone with Local Authorities and other lead practitioners to both gather feedback and highlight specific stories and people that we may want to follow up with.

In practice:

Two enlightening phone interviews were conducted by Jennifer Skinner with people who had run the training: Ray Mowat, Lakeland Carers, Cumbria and Sean McGregor of Dumfries and Galloway Local Authority.

Ray highlighted the way he used the resource: He asked the students to design a care plan for Ann as a practical task. Sean asked us if we could design a See Beyond Stroke certificate for people who had completed the training, as these would be particularly useful to demonstrate what they were doing to the Care Commissioner. We adopted this suggestion.

(See Appendix 3)

### 2.4 Monitoring our Time Commitment

Our See Beyond Stroke activity was planned to run from July 2016 - March 2017. The project ran over into August 2017, due to the challenges outlined above in reaching decision makers, plus the need to fit in with existing training schedules to make our Pilot happen.

### In total, the Bertha-supported activity took 1139 hours to deliver (142 days or 28.5 weeks full-time equivalent) across the staff team.

Karen Guthrie oversaw the initial desk research conducted by an intern (26 hrs) and thereafter took a lesser role, monitoring the project weekly and posting on social media, and using her personal contacts wherever possible to secure participation. When it was clear that more accessible and explanatory materials were needed as part of the See Beyond Stroke training resource, Karen wrote and redesigned the existing PDFs and updated the website accordingly as we had not allowed for this activity in our project budget.

Karen Guthrie's total hours were 150 against an anticipated commitment of circa 60. Co-producer Nina Pope committed 22 hours working on financial management.

Distribution Producer Sally Hodgson's main tasks were:

- Managing the delivery of the SBS Pilot in 20 Local Authorities and the Stroke Forum activity (DVD giveaway, presentation & evaluation).
- Managing Jennifer Skinner
- Organising and chairing team catch-ups to monitor progress and devise solutions to challenges.
- Responding to query emails regarding the impact work
- Exploring other potential avenues for the resources (e.g. Skills for Care and licensing) and deliver the training resources accordingly.

Sally's total hours on the project were 500 against an anticipated commitment of circa 150.

Evaluation Officer Jennifer Skinner's main tasks were:

- Designing and implementing bespoke evaluation tools that gathered data and feedback from all audiences accessing the film via impact activities.
- Attending to funders' specific evaluation requirements and integrating these into the bespoke evaluation tools.
- Delivering the See Beyond Stroke Training Pilot to a target of 20 authorities in conjunction with Sally Hodgson.

Jennifer's total hours on the Bertha-supported work were 441 (376 on the See Beyond Stroke Carer Training Pilot) against an anticipated commitment of circa 200.

### 2.5 Feedback

The responses we received from people who ran See Beyond Stroke training sessions and those who participated, powerfully reinforced why we set-out to run this challenging project.

The Carer Worksheet asked a number of prompting questions to facilitate discussion and to get people thinking about their role and the lives of the people they care for.

The majority of the responses said that the resources had made them proud to be a carer. Limited time and resources were their main challenges, and the clips made carers much more aware of working with families and treating everyone they meet as an individual. An appetite for more training was also a response that came up frequently as well as the need for more equipment and time with the stroke survivor.

### The following selected comments have been transcribed from the Carer Worksheets received from people who participated in the training:

#### How did the clips make you feel about your role?

'Proud to be able to help keep to a routine as similar to their old one as much as possible'

'Made me feel important in my role as a carer and how much we are valued, I am very privileged.'

'I am an important part of the individual's life and of their families. It is important to make a connection and to really get to know them both.'

#### How can professional carers and care givers share responsibility?

'Effectively communicate and document all actions and tasks. Be truthful. Be respectful of each other.'

'Communication, time and continuity' 'Sharing information and offering support to family members'

#### What are the challenges facing you as a carer, working in someone else's home?

'Family, environment, timescale, resources and equipment' 'Be mindful of their values and respecting that you are invading a person's personal space' 'Overstanning boundaries, being respectful of their space and wants'

'Overstepping boundaries, being respectful of their space and wants'

#### Which activities seemed to benefit Ann the most?

'Personal care and encouragement' 'Sense of achievement' 'Interaction benefitted her the most - physical and mental'

#### How have the clips affected your perceptions of stroke survivors?

'Look at the unique individual, concentrate on remaining abilities, treat the person with respect.'

'That their quality of life may have deteriorated - however they still have their thoughts, feelings and memories and their time should be made precious' 'I have a better understanding of how the family members felt after Ann experienced the stroke and how big a change it was for them'

#### How might you change how you work with stroke survivors now?

'To help them be as independent as possible'

'Treat them more as a person who knows what they want – give them more choices'

'As a manager I will look at ways of providing further training and awareness for teams'

'Ensuring time is given to allow tasks to be completed without rushing' 'See the person not the stroke'

'Putting them first, listening and communicating, giving choices and time'

#### What could you change about your next day at work?

'Reassess abilities of each person, keep the person involved in the process' 'Be more inclusive when communicating with an individual, try to ask open-ended questions'

'Offer more help to family members. Spend more time with the person and not on the task'

'Allowing the time to do what tasks they can manage on their own and not to take that away from them'

#### We were also keen to gather feedback on the design of the resource itself.

The **Trainer Feedback** form allowed us to gather this selected feedback:

#### How were the resources useful?

'This training was useful to look at things in the bigger picture and allowed me to reflect on my working practices and how I can change the ways in which I support an individual who is a stroke survivor.'

'Informative - prompted me to reassess certain aspects of my role, to ensure best practice possible'

'Very useful, especially the clips to observe action'

'Gave an insight to good teamwork between carers and family'

#### How were they useful to the staff present?

'The clips were personal so they enhanced the importance of the person-centered care as the carers could really relate to them'

'Video clips and questions are a great source for training as it allows us to look at real-life situations and allow us to put ourselves into their shoes'

#### How could you use them in the future?

'As a refresher'

'We are going to use these resources to help improve and enhance the quality of care that we provide not only to those who are stroke survivors but also to others who suffer from severe health implications.'

'Engaging with new service users in a positive and possibly different way'

# 2.6 Carer Training Pilot - What We Learnt

- How UK adult domiciliary social care provision is managed and delivered is highly variable from place to place - therefore there is no 'one size fits all' training solution for all carers working in the public sector across the UK.
- The project would have benefitted from running for a longer period of time, with distinct phases for Research & Development, Implementation and Evaluation. This would have helped with maximising the positive connections the team made and could have lead to achieving the target number of See Beyond Stroke training sessions taking place.
- Trainee Evaluations showed that the content of the Pilot is engaging, thoughtprovoking, and above all, watchable. This should ensure it remains relevant and useable in the future, offering us future opportunities for income streams licensing the resources to carer trainers.
- Reaching those that could make decisions regarding carer training was extremely time-consuming, yet when successful, the take-up of the Pilot was high. Further administrative support to locate and secure LA contacts should have been included in our project budget, or perhaps in-kind support sought from a partner organisation with suitable staff to do so.
- Personal contacts were invaluable in cutting through bureaucracy.
- Carers and even care managers / trainers are often working without access to IT, and so the required alternatives to efficient online delivery and evaluation demanded much more administration and input from our team.
- We were too ambitious in terms of setting out to create bespoke materials on a case-by-case basis.
- With the geographical spread of the core team, an allocation of funding for the team to meet-up in person on a regular basis would have been a big benefit, enabling us to sit down together and discuss progress, overcome issues and forward plan expediently.
- How vital it is to have good administrative and project monitoring tools in place. To keep the project up-to-date and on track as far as possible the team relied heavily on a shared Google Drive folder and documents and also Skype.
- We underestimated the time / skills required to write, design and fine-tune copy on the kit's PDFs and should have allowed for this in our budget.

### 2.7 Associated Outcomes

A number of related achievements originated in the Pilot Carer Training activity:

#### Licensing the See Beyond Stroke resource for online learning

We worked with two major deliverers of training to offer the resource through their online learning systems:

#### Greater Manchester Stroke Operational Delivery Network (GMSODN)

The Closer We Get and the See Beyond Stroke resource is now licenced for use through the GMSODN's online teaching tool, in part facilitated by the commitment of Stroke Association North West's staff and board members to our work. This tool is aimed at NHS professionals in Greater Manchester across a range of roles. The expected reach is approx. 150 people. annually.

"The film and clips will be very useful additions in teaching clinical staff in hospitals, community and primary care."

Sarah Rickard, Network Manager

#### Stirling University

Dr. Sandra Engstrom, Social Work Lecturer in the Faculty of Social Sciences at the University of Stirling instigated an educational licence for **The Closer We Get** following Karen screening the film and leading a discussion for students and the public at the MacRoberts Arts Centre within the University.

The See Beyond Stroke resource was offered as part of the event. Dr. Engstrom saw its potential for use within the University's Social Work modules and it now forms part of undergraduate and postgraduate teaching.

As of June 2017 the 22 students on the undergraduate module had accessed the resource 61 times with the 29 students on the postgraduate module accessing the resource 37 times. This clearly shows a repeated use of the resource and informally validates its usefulness to people studying within the field of Social Work, an avenue we hope to explore further.

As both of these clients wanted an enhanced version of See Beyond Stroke, we were able to generate income from these relationships and hope to build on this with new clients in the future.

#### **Profile at Events**

Karen has spoken at a number of events as a result of See Beyond Stroke: 'The Dust of Everyday Life' - a Scottish Mental Health Arts & Film Festival / Mental Health Foundation event highlighting relationships between mental health and creativity.

"Deep in the Heart of Your Brain' - a symposium by Glasgow Life (i.e Glasgow City Council) and artist Jacquie Donachie that discussed the links between risk, bravery and discovery in science and in the creative arts.

Karen also appeared on BBC Radio 4's 'Women's Hour' to discuss care-giving.

#### **Skills For Care**

To address the initial slow take-up of our training resource, contact was made with Skills For Care - the strategic body for workforce development in adult social care in England. Through them we were put in touch with their list of approved training suppliers to offer our resource - this had a good take-up, with our resources being used by three major companies in 25 Local Authority areas. However, we have not included this figure in our overall tally as our target of domiciliary care workers was not reached through this activity - instead the training was delivered predominantly to people working in care home settings.

(For a full list see Appendix 5 - Additional Local Authorities)

### APPENDICES

Appendix 1 - Feedback from UK Stroke Forum (2 x examples)

Appendix 2 - Stroke Association Evaluation Questionnaire Responses

Appendix 3 - Carer Training Pilot - The Resource Kit PDF's

Appendix 4 - See Beyond Stroke List of Participating Local Authorities

Appendix 5 - See Beyond Stroke List of Additional Local Authorities

### Appendix 1 -Feedback from UK Stroke Forum (2 x examples)

#### UK STROKE FORUM 2016 – WORKSHOP FEEDBACK

Please share your thoughts on this workshop as they are important for our ongoing outreach work. Thank you

1. What message does the film workshop offer healthcare professionals, including carers?

much it ward be incredibly important for professionals in hospital selfing and at home to remind people met creisone is houridad + studie impalts a hige network, of people around the Strate similias in such a difficult 2. After watching these clips is there anything you would do differently? Church Ment in NHS& LAS. 1 work with strate & minors + carers all we time but in a management capacity - I will

use the Cuips Luith pennission!) with teams and work hardler to put the caper + their loved one above atteances? 3. What needs to change?

4. How can we make these changes? As many people as possible need to see the film t engage with it. I dennitery agree that consuments a commissioners would perefit

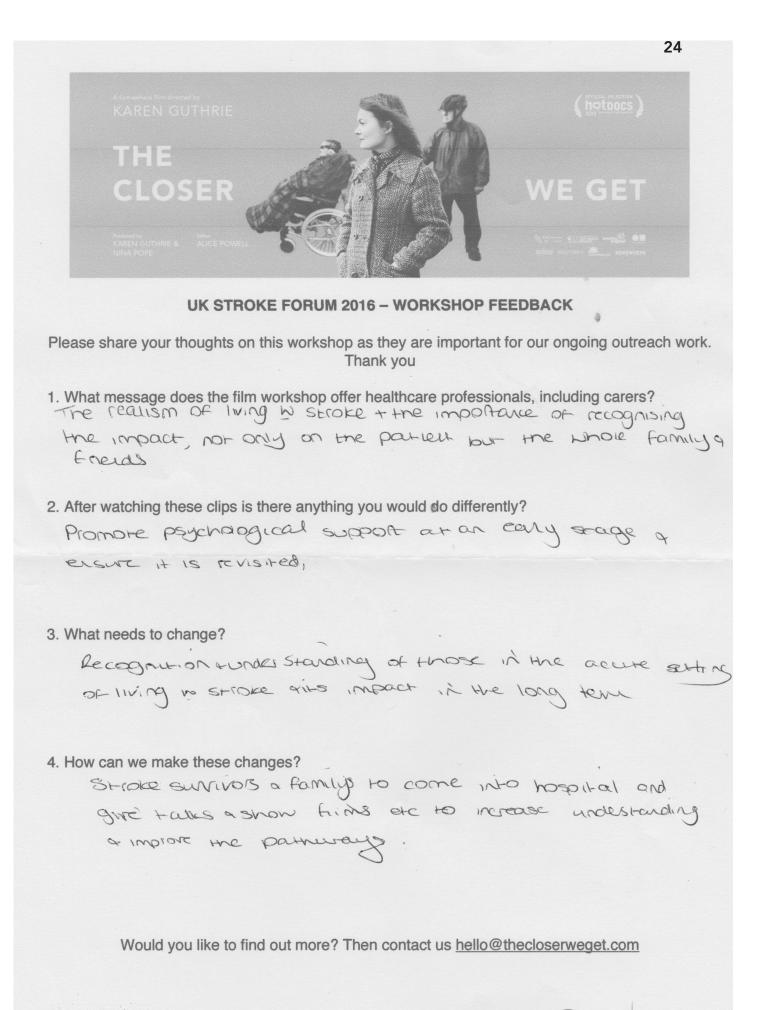
> Would you like to find out more? Then contact us hello@thecloserweget.com I have a carple of armanit

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# Appendix 2 -Stroke Association Stroke Forum Evaluation Questionnaire Responses

#### Our question was:

'With reference to the DVD of 'See Beyond Stroke' clips you received in your delegate pack: The creators of See Beyond Stroke can offer engaging film-based training tailored to your specific requirements. Are you interested in finding out how film content could be used as a learning resource within your area of work?'

PROFESSION		Ν
Other	8	14
Physician	19	38
Physiotherapist	11	13
Psychologist	3	0
Researcher	7	14
Speech and language therapist	4	6
Stroke co-ordinator	3	1
Other	2	18
TOTAL	96	236

## Appendix 3 -The Carer Training Pilot Resources (4 x PDFs)

These were all made available by email, to download from **www.thecloserweget.com/sbs** or by post. Since the Pilot ended they have been modified, but remain online and available for use.

# THE CLOSER

### **SEE BEYOND STROKE** advice for trainers: how to use the resources

All materials are available for free! Download them from www.thecloserweget.com/sbs or contact Jen (details below)

### 1 -

#### prepare

We recommend setting aside an hour for the training session - this gives enough time for talking, for the written feedback and for watching.

Beforehand, check that your online links or DVD of the Clips works okay & that you've enough printed copies of the CARER WORKSHEET (2 pages) for everyone taking part.

Have a look at the film website at www.thecloserweget.com/sbs

#### 

DVD and online copies of **The Closer We Get** are available for carers participating in this programme. Please ask for details.





#### TheCloserWeGet

### 2-

#### explain & watch

Provide all participants with a printed copy of the CARER WORKSHEET. Let them know we will be taking copies of these, but that they can write as much or as little as they like.

Read over our questions together before watching as many of the Clips as possible.

#### **3**▼ talk & feedback

A good way to begin the feedback session is by asking,

"What are the most important qualities that a carer needs?"

Encourage the trainees to talk together before completing their worksheets individually.

Lastly, complete your TRAINER EVALUATION.

#### 4 🕶

#### copy & return

Make clear copies of the completed worksheets & your evaluation to return to us. These can be phone pictures or photocopies / scans. Email scans / phone pics to jen@somewhere.org.uk

OR post photocopies to Jen Skinner, See Beyond Stroke

Please try to do this within a week of the session. Feel free to keep the original copies.

### Questions? Call Jen on

britdoc

BERTHA



### **SEE BEYOND STROKE carer worksheet**

These **See Beyond Stroke** training resources are based on the awardwinning British documentary, **The Closer We Get** - a funny, uplifting and poignant film that follows the impact of a stroke suffered by director Karen Guthrie's mother Ann, a former nurse. Karen became one of her care-givers at home in Largs, Scotland, supported by family and a team of local carers.

#### Read more about the film at www.thecloserweget.com

Enjoy the Clips and thank you for taking part. If you use social media, please get in touch with #seebeyondstroke





TheCloserWeGet

Your name

Your contact details phone & email if possible (we won't share these with any other parties) Gender

How long have you worked as a carer?

Your present local authority or company

#### (1)

The Clips show carers taking part in the everyday life of Ann & her family

How did the Clips make you feel about your role, and how you fit in to clients' day-to-day lives?

#### (3)

What are the challenges facing you as a carer, working in someone else's home?

#### (2)

How can professional carers and care-givers (such as friends and family) share responsibility?

#### (4)

### The Clips show Ann engaged in many different activities.

Consider anything on screen that may have given you cause for concern if you'd experienced it. Which activities seemed to benefit Ann the most, and how?



### SEE BEYOND STROKE carer worksheet (continued)

Your name

#### (5)

Ann's stroke took place in 2008, and she died in 2013. Most of the filming took place in 2011/12. How have the Clips affected your perceptions of stroke survivors?

#### (7)

Based on your responses to the Clips, what could you change about your next day at work, big or small?

#### (6)

How might you change how you work with stroke survivors now?

#### (8) Please use this space for any other comments

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	Date	
Karen J Guthrie (Dire		@TheCloserWeGet @TheCloserWeGet



### **SEE BEYOND STROKE trainer evaluation**

Your name:	As a trainer, how were the Clips & Worksheets useful to you?
Job title:	
<b>Your contact details -</b> <b>phone &amp; email if possible:</b> (we won't share these with any other parties, but we may get back in touch with you during our evaluation)	How were the Clips & Worksheets useful to the staff present?
Your local authority or company :	We hope you can make long-term use of these resources. How could you use them in the future?
return your evaluation & the carer worksheets to us:	Please let us know what we could have done (or be doing now) to make this Carer Training Pilot easier for you?
Email scans / phone pics to	
OR	
Post photocopies to Jen Skinner	Please use this space to make any other suggestions or comments.
@TheCloserWeGet #seebeyondstroke	
© Somewhere, J Goodings Pie & Mash, 257 Well St, London E9	or ARG www.thecloserweget.com

### Appendix 4 -See Beyond Stroke Participating Care Trainers & Local Authorities

Training Delivered By	Local Authority
Tiree Care Home and Homecare	Argyll & Bute
Frimley Health NHS Foundation Trust	Berkshire
Birmingham City Council	Birmingham City
Blackpool Carers Centre	Blackpool
Lakeland Carers	Cumbria
Dumfries & Galloway Council Care and Support Services	Dumfries & Galloway
Constance Care, Mears Group, Care Watch, Hazelhead Home Care, Rainbow Care Services, Hera Home Care	East Ayrshire
Frimley Health NHS Foundation Trust	Hampshire
Highland Council, Thurso Area Office, (Children & Families/Community Care)	Highlands & Islands (Caithness)
Ings Grove House - Support to Stay at Home services	Kirklees
Gtr Manchester Stroke Operational Delivery Network	Greater Manchester
North Ayrshire Health and Social Care Partnership	North Ayrshire
Pembrokeshire County Council	Pembrokeshire
Frimley Health NHS Foundation Trust	Surrey

### Appendix 5 -See Beyond Stroke Additional Local Authorities

Additional Authorities where carers have been reached with our resources via the 'Skills for Care' training provider

Company / Agency Delivering Training	Local Authority
Maria Mallaband Care Homes	Blackburn
Maria Mallaband Care Homes	Bradford
Maria Mallaband Care Homes	Blackpool
Maria Mallaband Care Homes	Cheshire East
Maria Mallaband Care Homes	Cheshire West and Chester
Maria Mallaband Care Homes	County Down - Northern Ireland
Maria Mallaband Care Homes	County Durham - Darlington, Durham, Newton Aycliffe
Maria Mallaband Care Homes	East Ayrshire - Auchenleck, Kilmarnock
Maria Mallaband Care Homes	Kirklees - Batley
Maria Mallaband Care Homes	Liverpool
Maria Mallaband Care Homes	North Lanarkshire - Motherwell

# Appendix 5 -See Beyond Stroke Additional Local Authorities (cont'd)

Company / Agency Delivering Training	Local Authority
Maria Mallaband Care Homes	Northumberland - Cramlington, Whitley Bay
Maria Mallaband Care Homes	South Tyneside - South Shields
Maria Mallaband Care Homes	Stirling
Maria Mallaband Care Homes	Tyne and Wear - Sunderland
Q Care	Cardiff
Q Care	Gloucestershire
Q Care	Herefordshire
Q Care	Monmouthshire
Q Care	Newport
Q Care	Rhondda Cynon Taf - Wales
Q Care	Torfaen - Wales
Quality Care Training Consultancy	Solihull